Review of Current Income Retention Rules

Report to the Illinois House of Representatives
Pursuant to House Resolution 0851

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Introduction

The Illinois House of Representatives adopted HR0851 on June 1, 2004. The resolution directs the Department of Public Aid (DPA) to:

1. Conduct a thorough review and analysis of the current income retention rules for persons with disabilities who are residing in nursing facilities in Illinois in regard to the impact of the rules (a) on the implementation of the Olmstead decision in general and (b) on whether the rules created a disincentive to engage in gainful employment for persons who are able, available, and willing to seek employment with or without supports.

2. Include in the review and analysis of current income retention rules recommendations on the feasibility of allowing persons with disabilities who reside in nursing facilities in Illinois and who are able and willing to move to more integrated residential settings to keep a larger portion of their income and deposit that income into Individual Development Accounts to allow for the accumulation of assets in order to transition into more integrated residential settings.

3. Consult with the Department of Human Services, appropriate advisory councils and committees, persons with disabilities and their family members, advocates for persons with disabilities, and other interested parties in conducting the review and analysis and developing recommendations.

4. File a written report, including findings and recommendations, consistent with this Resolution, with the House of Representatives on or before December 31, 2004.

The resolution also directs the Department of Human Services to cooperate in executing the requirements of the resolution. A copy of HR0851 is appended.

DPA completed its review and analysis with the assistance of staff at the Departments of Human Services (DHS) and Aging (DoA). In addition, DPA held a public meeting via video conference in Chicago and Springfield on December 14, 2004 to solicit the comments and recommendations of persons with disabilities and their family members, advocates for persons with disabilities, and other interested parties. Materials for the meeting were available in large print and a sign language interpreter participated. A copy of the meeting notice is included in the appendix to this report. More than 50

people participated in the public meeting. The issues raised and comments received at the public meeting are discussed later in this report.

Medical Benefits Overview

DPA provides comprehensive medical benefits to residents of Illinois who are children, parents or caretaker relatives raising children younger than 19, pregnant women, seniors 65 years of age or older and persons who have a disability or blindness. The comprehensive health care programs for these groups are known as KidCare; FamilyCare; Moms and Babies; and Aid to the Aged, Blind and Disabled (AABD) Medical respectively. Additionally, DPA operates a number of less comprehensive health care programs such as the SeniorCare prescription drug program and the Illinois Healthy Woman family planning program. Generally speaking, to be eligible individuals must be U.S. citizens or qualified immigrants.

AABD Medical covers persons who are seniors (age 65 or older) or who have a disability (based on Social Security definitions and largely dependent on whether the individual is unable to work) or are blind. For persons who live in the community, including persons residing in DHS approved residential settings, an eligible single person may have income up to 100 percent of poverty ($776 per month in 2004) and no more than $2,000 of countable assets. A couple may have income up to $1,041 per month in 2004 and up to $3,000 of countable assets. Some assets are not counted. These include the person's home, certain motor vehicles, life insurance with a face value of $1,500 or less, burial spaces and specific prepaid burial plans. Illinois receives federal Medicaid matching funds for services provided to persons enrolled under this category.

Persons enrolled under AABD Medical are covered for a comprehensive array of health services including doctor visits and dental care, specialty medical services, mental health and substance abuse services, hospital care, emergency services, prescription drugs, family planning, and medical equipment and supplies. AABD Medical covers long term care services in skilled or intermediate care nursing facilities (SNF and ICF) or Intermediate Care Facilities for persons with Developmental Disabilities (ICF/DD) including state operated developmental centers. Currently, for every dollar the state of Illinois expends on these Medicaid services, the federal government reimburses Illinois 50 cents.

Since the 1980s, the state of Illinois has sought to expand options for beneficiaries in where they may receive services. By way of several specialty programs known as home and community-based services waivers, Illinois has expanded the support that beneficiaries may receive to avoid institutionalization. Illinois now operates seven home and community-based services waiver programs. Under waiver programs, community residential alternatives include Supportive Living Facilities (SLFs) and Community Integrated Living Arrangements (CILAs).

Current Income Retention Rules

The Medicaid rules governing the treatment of the income received by persons residing in an institution are set in federal law. Under federal Medicaid law, an institution means SNFs, ICFs, and ICFs/DD including state operated developmental centers. As of the end of November 2004, DPA paid for care provided to approximately 58,000 persons residing in SNFs and ICFs. In addition, DHS paid for care provided to 7,000 residents of ICFs/DD and 3,000 residents of state operated developmental centers.

The disposition of the income of persons residing in DHS approved residential settings or receiving other supportive services through Community Integrated Living Arrangements (CILAs) **is not** governed by DPA's rules regarding how much a resident must contribute to the cost of their care in an institution.

Illinois' rules concerning eligibility for medical assistance and the amount of income that persons residing in medical institutions must apply toward the cost of their care are based upon federal Title XIX of the Social Security Act and are designed to maximize the amount of federal matching funds the state may receive for covering the person's care. Countable income can be either earned or unearned. However, DPA disregards a portion of the earnings of employed persons. For employed persons who reside in a SNF, ICF, or ICF/DD, DPA disregards $20 plus one-half of the next $60 per month of the monthly earnings of persons who are aged or have a disability and $85 plus one-half of the remainder of the monthly earnings of persons who are blind.

In addition to Illinois' Medicaid rules outlined above, it is important for the purposes of this report to understand what happens to federal benefits paid as Supplemental Security Income (SSI) when a person enters an institution. Title XVI of the Social Security Act governs SSI. The purpose of the SSI program is to avoid destitution of the aged or persons with disabilities. SSI provides a minimum level of income for persons age 65 or older, and persons who have a disability or are blind. Eligibility is not based on prior work but on financial need. The SSI rate for a single individual is $564 per month in 2004 and will increase to $579 per month in 2005.

The federal government reduces SSI benefits for persons who enter a SNF, ICF, ICF/DD or state-operated Institution for Mental Diseases (IMD) to $30 per month. However, SSI benefits may continue for persons who are temporarily placed in a SNF, ICF, ICF/DD or state-operated IMDs for a period of 90 days or less. The Social Security Administration (SSA) must approve the continuation of SSI benefits at the regular monthly amount. Receipt of SSI during the temporary stay provides a means of payment of some or all of the expense of maintaining a home to which the person may return upon discharge. SSI benefits are not reduced for persons who enter a private IMD.

Social Security retirement and disability benefits under Title II of the Social Security Act as well as state or private sources of income are not reduced upon entry to a SNF, ICF,

ICF/DD or IMD. These benefits, in contrast to SSI, are based on prior work and contribution to Social Security.

Federal Medicaid rules regarding eligibility for institutional care are found in the Code of Federal Regulations at 42 CFR 435.733 and 435.832. These regulations provide that for persons residing in long term care facilities (SNFs, ICFs, ICFs/DD including state operated developmental centers), monthly earned and unearned income is totaled together. Any nonexempt assets in excess of $2,000 are added to this amount and the total is compared to the cost of care at the private rate.

If total monthly income is less than the cost of care at the private pay rate and there are no excess assets, the individual is eligible for medical benefits and is issued a monthly MediPlan card, provided they meet the other eligibility criteria such as residency or immigration status.

If total monthly income or excess assets are greater than the cost of care at the private pay rate, the individual is enrolled in the program known as spenddown. Spenddown allows an individual to subtract the cost of their medical care from their income so as to qualify for Medicaid. For instance, if an individual's income was $100 above the AABD Medical income threshold and if the person had incurred $100 or more in medical expenses, this amount would be subtracted from the individual's income and he or she would qualify for AABD Medical in that month. Individuals enrolled in spenddown are not eligible for DPA payment of medical expenses until spenddown is met. Spenddown is met on the day in the month that allowable expenses meet or exceed the spenddown amount. Medical benefits are authorized from the met day through the last day of the month. The individual must meet the spenddown amount each month to receive medical benefits.

Federal regulations at 42 CFR 435.733 and 435.832 provide that the state must reduce payments to long term care facilities by the amount remaining after specified deductions are made from the income of institutionalized persons. Income remaining after these deductions is the amount residents must pay toward the cost of their long term care services. If DPA increases the maximum amount of any of these deductions, DPA's cost for the person's care in the institution increases by an equal amount.

The mandatory and optional deductions are outlined below.

<u>Mandatory Deductions:</u>

- Personal Needs Allowance (PNA) of at least $30 per month;
- Maintenance Needs of A Spouse At Home. Illinois uses the federal maximum of $2,319 per month for 2004 and $2,378 per month effective 01/01/05;
- Maintenance Needs Of A Dependent Family Member At Home ($520.33 per month in 2004); and
- Medical Expenses, including premiums for private health insurance.

Optional Deduction

- Maintenance Of The Person's Home. The Department provides for this deduction. Federal regulations require that the amount is deducted for a period that does not exceed six months, and that a physician has certified the person is likely to return home within that period. Income deducted for this purpose that is carried over from the month it is received is counted as a nonexempt asset in subsequent months and is, consequently, subject to the $2,000 limit on nonexempt assets.

Interaction of Eligibility Rules and the *Olmstead* Decision

The 1999 Supreme Court ruling in *L.C. & E.W. vs. Olmstead,* 527 U.S. 581 (1999), interpreted the Americans with Disabilities Act (ADA) to mean that states must provide services in the most integrated setting appropriate to the needs of qualified individuals with disabilities. The ruling directs states to make reasonable modifications in programs and activities. Modifications that would fundamentally alter the nature of services, programs or activities, however, are not required. Further, the *Olmstead* decision does not mandate specific action to the state but rather requires that the state take reasonable measures to implement the decision. The determination of what is reasonable depends on the specific state situation, including budgetary constraints and the totality of state programs.

Facilitating the ability to set aside funds for transition to the community is consistent with the *Olmstead* decision. However, all such changes to the program must be done in such a way that does not jeopardize the federal financial support for the current medical programs. The loss of federal matching funds would constitute a fundamental alteration of the program and would jeopardize the financial sustainability of the overall Medicaid program, including the benefits offered to the AABD Medical population as a whole.

DPA has determined that the *Olmstead* decision does not mandate a particular position regarding income retention policy. DPA has not identified any state that has been compelled by the courts to modify income retention policy as a result of the *Olmstead* decision.

Interaction of Eligibility Rules with Employment

There are many different barriers to employment for persons with disability. Since any countable income (disregarded earnings as described previously are not "countable" income) of any kind, earned or unearned, and in excess of the $30 PNA must be applied toward the cost of a resident's institutional care, it is likely that the current income retention policy discourages persons in institutions from working.

There is, however, an even greater disincentive for work embedded in federal law regarding eligibility based on having a disability. Since the determination of whether an individual has a disabling condition is largely based upon whether the individual is able to work, engaging in paid employment can actually place an individual's cash and

medical benefits at risk, should they be found to no longer have a disability. This point was made at the public meeting regarding HR0851.

The Congress has recognized this issue and has attempted to address it through the Ticket to Work Program that gives persons with disabilities a longer period of time to transition from public benefits to work. In support of this effort, Illinois has established medical assistance coverage under Health Benefits for Workers with Disabilities (HBWD). Through HBWD, persons with assets of up to $10,000 and income up to 200 percent of poverty can pay a premium and "buy-in" to medical benefits. Illinois has modified the process for determining disability for HBWD applicants so that work does not disqualify them. Although this program mitigates the risk of total loss of benefits, it does not eliminate it. HBWD is also more likely to fill the needs of individuals who are already living in the community, and in that respect, may offer more assistance for individuals after they transition out of an institution.

With a similar objective in mind, the federal government established PASS: a Plan for Achieving Self Support primarily for SSI beneficiaries. Under PASS, SSI beneficiaries may set aside income or resources for a specified time for a work specific goal. (People who receive Social Security Disability Income (SSDI) may qualify if they set aside the SSDI check into the PASS account, thereby becoming eligible for SSI.)

Money may be set aside to pay educational expenses, vocational training, or to start a business as long as the expenses can be tied to an occupational goal. Persons may maintain eligibility for SSI cash assistance while setting aside earnings or resources in a PASS account.

Advocates and consumers at DPA's public meeting on HR0851 expressed concern over the complexity of PASS. A PASS must:

- Be designed just for a specific beneficiary;
- Preferably be written on the Social Security Administration (SSA) form 545-BK (or a similar form);
- Have a specific time frame for reaching the goal;
- Identify money other than Social Security payments that the person will use to reach the goal;
- Show how money will be kept separate from other funds;
- Be approved by SSA; and
- Be reviewed by SSA as SSA determines necessary to assure progress is taking place.

If approved, SSA will not use any PASS funds to determine eligibility for SSI cash assistance, nor will funds be counted as resources. PASS accounts are defined as work incentive tools. SSA does not mention anything about living arrangements in PASS discussions.

Since PASS goals are occupational in nature, PASS does not directly address the issue of deinstitutionalization. PASS's applicability to this issue is further complicated because SSI benefits, as described above, are significantly reduced for most persons residing in institutions.

DPA has identified one other complicating factor in federal eligibility policy. Any income retained by a facility resident that is carried forward must be treated as a nonexempt asset in subsequent months. Any nonexempt assets in excess of $2,000 for an individual must be applied toward the cost of the individual's long term care.

Individual Development Accounts

Individual Development Accounts (IDAs) were developed under federal law to allow certain individuals to set aside money for specific purposes. Under these laws, IDAs are not included as resources when determining eligibility for certain federal entitlement programs such as Medicaid.

The Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (PRWORA) enabled certain recipients of Temporary Assistance to Needy Families (TANF) to establish and maintain IDAs. Under current federal law, however, this program is not applicable to persons eligible for AABD Medical.

The Assets for Independence Act of 1998 (AFIA) also supports the development of IDAs. Under this Act, federal grant funds were made available beginning in 1999 to match the individual's contributions to an IDA. Currently, however, no additional grant funds are available. The recent bill to reauthorize AFIA has died in committee. It is unknown if further efforts will be made to fund this initiative.

Further, AFIA is specific as to the purposes for which funds deposited into IDAs can be used. The IDAs must be used for home ownership, post-secondary education or microenterprise development. None of these uses will effectively assist in the transition of persons from long term care institutions to the community. Therefore, the use of IDAs to facilitate the goal of deinstitutionalization appears not to be feasible under current federal law.

Other Options for Financing Community Reintegration Costs

Since federal law precludes the establishment of IDAs by persons seeking to retain income to enable them to move out of institutions, DPA reviewed state and federal law to determine whether other methods of retaining income or financing community reintegration costs were available. In its review, DPA sought options that would minimize the loss of federal matching funds and that would not put a significant financial strain on the state, which might in turn jeopardize other benefits or beneficiaries. The department identified several related policies.

1. Federal regulations permit the Department to set the amount of the previously mentioned optional deduction for the maintenance of the person's home. This is

available to persons who already have a home and for that reason, would most likely be useful to persons when they first enter an institution. This would also increase DPA's costs but data is not available to estimate by how much.

2. Federal law requires a minimum PNA of $30 per month for an institutionalized person. Illinois is permitted to increase this amount if it is increased for **all** institutionalized persons. DPA estimates that increasing the PNA to just $50 per month has a gross fiscal impact of approximately $14 million annually. In addition, since DHS takes the amount of the PNA into account in determining the AABD cash assistance standard for a person in sheltered care, any change DPA made to the PNA could result in increased costs to DHS as well.

3. Illinois may increase the PNA for institutionalized persons who are employed. Illinois would have the option to set the PNA at an established amount for all of the employed residents or use a PNA based on a percentage of earnings that establishes a different amount for each employed resident. These amounts must be reasonable and based on need. Federal law prohibits the State from increasing the PNA for unemployed residents even if they have a potential for employment or from increasing the PNA just for persons seeking to leave the institution. Also, the increase would have to apply to all persons who work regardless of whether they plan to use the retained earnings to reintegrate to the community.

4. Illinois could attempt to obtain a Section 1115 research and demonstration waiver from the Secretary of the U.S. Department of Health and Human Services to create specific income retention changes. Such waivers are limited to a five-year period and must be cost neutral

5. Costs for one-time set-up expenses for a security deposit, utility hook-up charges, essential furnishings, home modifications and moving to a residence in the community are allowable under home and community-based services waivers at the discretion of the state. This service may not include payment of rent. The state would also be responsible to pay one-half of these costs.

Review of Past, Current and Developing Reintegration Efforts in Illinois

Having enough income to establish and maintain a home in the community is one element of a complex set of supports that persons are likely to need to successfully leave an institution. Illinois has had experience with community reintegration efforts and recent legislation has called for more work in this area. These efforts are described below to provide a broader context for consideration of income retention policy.

Transitional Assistance Program

The Transitional Assistance Program (TAP) was a joint agency initiative of the Department on Aging and DPA. This pilot deinstitutionalization program was initiated in

the fall of 1996 for the identification and discharge or placement of nursing facility residents receiving AABD Medical benefits who were ready and able to return to their own homes or independent living settings. This initiative focused on identifying and discharging residents who needed the nursing facility level of care upon admission, remained in the facility for 6 months or more and whose health had improved to the point that they no longer needed moderate to heavy level of care.

Six counties were selected for the pilot project: Adams, Cook (two geographic areas) Kankakee, Livingston, Macon, and McDonough. A total of 61 facilities from these counties were invited to participate. Of these, 12 facilities volunteered for the program. The facilities were asked to submit the latest Minimum Data Set (MDS) assessments of all AABD Medical residents who had been in the nursing facility for 180 days or longer.

Working with sister state agencies, DPA developed a TAP screening instrument to identify the lighter need nursing facility residents for referral for discharge evaluation. DPA staff completed the TAP screening instrument using the data recorded on the MDSs submitted by the participating nursing facilities. All residents scoring as having potential for discharge on the screening instrument were referred to the designated DoA regional case management agencies. The case management agencies made visits to the facilities to complete a discharge evaluation on the residents referred by DPA.

Discharge planning was to be initiated on residents determined ready for discharge and for whom discharge was determined appropriate. Procedures were developed to set aside two months of the individual's income that normally would go toward their nursing facility care for the purpose of re-establishing the person at home or an independent living setting.

MDSs for 365 residents in the facility 180 days or longer were submitted from the 12 participating nursing facilities. Of these, 144 were identified as light need. Of the 144, 22 were not referred for discharge evaluation either because of mental health history or clinical status and 122 cases were referred to DoA case management agencies for a discharge evaluation. The results of discharge evaluations were submitted on 103 of the 122 residents. Discharge planning was not recommended or initiated for any of them: 49 were determined not appropriate for discharge due to medical or mental diagnoses and the remaining individuals chose not to leave the facility.

This outcome was very disappointing. One conclusion drawn from the effort was that limiting TAP screening to longer term residents contributed to the lack of success. This suggests that reintegration efforts should be focused on persons who are admitted for short term stays and work on discharge should begin as early as possible during the course of the stay.

DHS-DRS HSP, HCBS Waiver and Community Reintegration Program

The Department of Human Services, Division of Rehabilitation Services (DRS) administers the Home Service Program (HSP) serving over 30,000 individuals annually.

The program offers an individualized, family-centered approach for people with severe disabilities. Through HSP these individuals can stay at home and live self-directed lives, functioning as active members of their communities and retaining control over the services they receive. HSP services include personal assistants, homemakers, maintenance home health, emergency home response, home delivered meals, adult day care, assistive equipment, environmental modification, and respite care.

Approximately 80 percent of the individuals in the HSP are eligible for AABD Medical and are served in three home and community-based services waivers. The waivers allow the state to claim federal match for home and community expenditures. Those not eligible for Medicaid, but who have non-exempt assets less than $10,000, are funded through state monies only, with no co-pays or other costs to the customers. A portion of these expenditures is claimed administratively and the remaining expenditures are used to support the Maintenance of Effort for the Social Services Block Grant.

The three HCBS waivers include persons with disabilities, first approved in 1983; persons with HIV/AIDS, approved in 1990; and persons with brain injury, approved in 1999. Over the past five years, the waivers have been amended to increase capacities and in 2003 included persons who enroll in HBWD. Individuals in HBWD can return to work, continue to receive home and community services and personal care assistance at work, if needed, and retain medical benefits.

The waivers have grown rapidly over the last few years. Expenditures for the waivers were approximately $76M for over 14,000 persons in 1999 and approximately $180M for over 24,000 persons in 2004. Expenditures for the entire HSP program were approximately $137M in 1999 and $310M in 2004. Only the waiver expenditures are eligible for federal match.

In 1998, DRS initiated the state-funded Community Reintegration Program, to help people with disabilities, ages 18 to 59, transition from nursing homes back into the community. State fiscal year 2005 marks the program's eighth year of operation. Since the inception, the program has assisted over 800 individuals to transition back into the community. The Community Reintegration Program provides assistance to individuals in overcoming the barriers that exist in transitioning to living independently, after living in an institution, by providing support and funding for various up-front costs such as first and last month's housing rental, accessible housing modifications and a limited supply of household items.

DRS contracts with Centers for Independent Living (CILs) to initially conduct eligibility determinations and plan for discharge of customers who meet HSP eligibility criteria. The Community Reintegration Program serves approximately 85 counties of the total 102 in Illinois. CILs conduct personal outreach visits to nursing home staff, social workers, medical personnel and hospital discharge planners to apprise them of the options persons with disabilities have for living independently in the community. Written materials on the program are also provided. The most prevalent form of referral is self-

referral. Once a CIL begins to work with a nursing home customer, many other residents come forward to seek out services.

The most common barrier for the Community Reintegration Program is finding affordable housing. Other challenges include accessing community mental health and substance abuse services, accessible transportation, and adequate oversight of medical care. Transitions require a significant up-front cost in case management for arranging services and establishing a home, along with more intensive monitoring post transition. Finding qualified caregivers is always a challenge and is expected to be even more challenging as more persons choose services in the community. Transitioning larger numbers of individuals would require a significant increase in funding for direct care staff, home modifications, assistive equipment and case management.

The historical funding and notable community reintegration statistics provided by DHS-DRS is displayed below. Note: This data is continuously revised as a result of ongoing data collection.

CIL Funding for Community Reintegration

FY	# of CILs	Expenditures ($000's)
FY98	4	$ 42.1
FY99	8	$ 410.3
FY00	8	$ 610.8
FY01	20	$1,301.0
FY02	20	$1,477.4
FY03	21	$1,581.3
FY04	22	$1,550.6
FY05	21	$1,597.1

Numbers of Reintegration with HSP Cases FY00 – FY04

	FY00	**FY01**	**FY02**	**FY03**	**FY04**	**Total**
Reintegrated in Year	92	174	160	161	155	742
With HSP Cases	76	156	132	117	87	568
Percentage with HSP Cases	82.6%	89.7%	82.5%	72.7%	56.1%	76.5%

Typical Customer Profile FY00 - FY04

Category	Average
Age at Time of Reintegration	46
Number of Months Customer was in Nursing Home	20
Amount Spent on Up-front Costs	$3,000
DON Score of Customers Served by the Home Services Program	52

Up-Front Expenditure Breakdown FY00 – FY04

Category	Percentage
Furniture/Appliance	47%
Household items	23%
Rent/Deposits	19%
Home Remodeling	4%
Other	4%
Equipment	1%
Groceries	1%
Utilities	1%
Total	**100%**

From FY2000 – FY2004, 742 persons returned to the community under this program. Eighty-one cases were closed in the same period. Reasons for case closure are described in the following table.

Community Reintegration Closure Reasons for FY00 – FY04

Closure Reason (n=81)	Percentage
Death	23%
Unable to be Located	21%
Reinstitutionalized	19%
Condition Improved	18%
Other	12%
Received Services from Another Provider	7%
Total	**100%**

Illinois Department on Aging Community Reintegration Program

In response to Public Act 093-0902 (HB 5057), the Department on Aging (DoA) is developing a program of transition services for individuals age 60 and older who reside in nursing facilities and choose to return to the community. The program will be

developed in consultation with nursing homes, case managers, Area Agencies on Aging and others interested in the well being of frail elderly Illinois residents. The transition services may assist individuals in setting up a household, if needed, after living in a nursing home. Services being considered include essential furnishings and initial supplies, moving expenses, security deposits, and set-up fees for telephone, electricity and heating. DoA will also explore developing service options that may include, homemakers, emergency home response, specialized equipment, home delivered meals, home modifications, and other services to assure the level of services needed to transfer the individual safely to the community. The services should be similar to those offered in the IDHS-DRS Home Service Program.

DoA has reviewed nursing home transition programs offered by other states and the DHS-DRS Community Reintegration Program. DoA's goal is to create a program that comprehensively addresses health, cognitive, social and financial needs of eligible nursing home residents who choose to live in the community. Initially, DoA plans to implement the program in selected areas of the state. DoA anticipates that a new home and community-based services waiver will be necessary to obtain federal Medicaid matching funds to support the program.

Discussion

DPA considered several key questions in its review and analysis of current income retention rules. These questions were shared and discussed with the participants who attended the public meeting on December 14, 2004. The participants also raised issues DPA had not identified.

1. Who makes up the target group for community reintegration?

   The participants at the public meeting expressed concern that HR0851limited its consideration of reintegration to persons who are able, available and willing to engage in competitive employment because the resolution does not define what this means. The group shared the view that many persons residing in institutions who may not be able to work may be able to live in community settings with appropriate supports.

   Other concerns were raised around the use of the term nursing facility in HR0851. Virtually all of the participants at the meeting agreed that reintegration opportunities should not be limited to persons living in nursing facilities nor should they be limited to persons who are competitively employed.

   DPA has generally concluded that the target group, however defined, should include people who can make the transition to community living successfully.

2. Is it reasonable to require that a change in income retention policy should be made only if it does not jeopardize the state's ability to receive federal Medicaid matching funds for the cost of a person's care?

Illinois is one of only a few states to avoid cutting benefits, provider rates or eligibility, while at the same time expanding access to health care during this time of fiscal constraints. The ability to sustain the Medicaid program for all beneficiaries relies heavily on maintaining federal matching funds and engaging in prudent cost containment. DPA is strongly committed to maximizing the availability of federal matching funds for its expenditures. The participants at the public meeting generally acknowledged this position.

3. How likely is it that changing the income retention policy would on its own, be enough to enable significant numbers of individuals to move out of institutions?

DPA recently surveyed other state Medicaid Directors and their staff for information on reintegration efforts. Where a reintegration program existed, state officials were asked which services were viewed as most important to successful reintegration. Case management for transition planning, resources for utility hook-up, purchase of certain furnishings and money for security deposits were mentioned as the most important services.

DPA determined, and participants at the public hearing generally agreed, that allowing persons residing in institutions to retain more income was not, in isolation, likely to result in many individuals reintegrating in their communities. Advocates and consumers alike, however, cautioned that this should not stand in the way of changing the policy.

4. Is it reasonable to limit any increase in the amount of income that could be retained to individuals who signed an agreement, or care plan or some other document indicating their intention to move out of the institution? What if DPA required that a resident retaining income had to be participating in a reintegration program offered by another entity such as DHS-DRS or DoA?

The participants at the public meeting were almost evenly divided on this question between those who believed requiring a plan or involvement of a supportive entity such as a Center for Independent Living (CIL) was reasonable if not necessary and those who felt any such requirement would create a barrier that many residents would not overcome. Participants pointed out that persons in institutions are largely unaware of the supports available for reintegration.

However, given that other supports are likely also necessary to facilitate reintegration, DPA would suggest that at least initially efforts be concentrated on those individuals who develop and attempt to execute such a plan. Without such targeting, it will be financially more difficult to provide a reasonable array of services such as case management and other supports necessary for reintegration.

5. How much money would a person residing in an institution need to accumulate to finance the transition to a different living arrangement? What would DPA need to

take into account in determining how much a resident would be allowed to accumulate?

The experience of the DHS-DRS Community Reintegration Program as described previously is that the average up-front cost for moving a person out of an institution is $3,000. Commenters at the public meeting suggested the need ranged from $2,500 to $5,000 depending primarily upon housing costs in the community. Several participants objected to the application of any cap on the amount of money a person might accumulate.

6. Where or by whom should accumulated income be retained to preserve its use for reintegration?

DPA has not identified a simple answer to this question, as retained income must be counted as an asset under federal law and is subject to the asset limits for eligibility. IDAs were explored as possible mechanisms but DPA has found the federal laws addressing IDAs to be too limited to assist in reintegration. It might be more efficient and simpler for the state to pay certain transition costs directly.

7. What criteria could DPA use to identify individuals who would be permitted to retain income while residing in an institution?

Establishing criteria to limit a change in income retention to persons who actually will move out of institutions is necessary to meet the goals of such a change and to keep additional costs to a minimum. Nonetheless, advocates and consumers were also divided on this question. Many individuals took the position that DPA should not establish any criteria or require that individuals identify the specific goal of deinstitutionalization before being permitted to retain income.

Because residents of institutions often lack knowledge of supportive services available to enable a return to the community, adding criteria or goal requirements would only make this barrier worse. Others at the public meeting as well as DPA recognize the necessity of using criteria or other requirements to target limited resources and make the program effective.

8. How long should the Department permit a resident to retain income without making the transition out of an institution? For example, what if the state required that the person move out of the institution within six months or the accumulated income would have to be applied to the cost of residential care?

There was wide consensus at the public meeting that six months is too short a time period for persons seeking to reintegrate to their communities. DPA was urged to allow up to 24 months for the transition process. On the other hand, 24 months may be too long as people find it more difficult to reintegrate after longer periods of institutionalization as appeared to be the case in the Transitional Assistance Program.

9. What would a change in income retention policy cost the state?

It is generally thought that persons who need long term care often can be served at less expense in the community than in an institution. Any savings that would accrue to the state, however, would be generated over time. Consequently, any change in income retention policy must be expected to initially increase state costs.

Using the DHS-DRS experience, DPA has estimated that the transition costs alone of moving 500 residents out of institutions and into their communities would be $1.5 million. To this would have to be added the costs of ongoing services in the community necessary to assure the individuals' health and safety.

Feasibility of Changing Illinois' Income Retention Policy

As described above, given the complexity of federal law regarding eligibility for Medicaid under Title XIX and income and disability benefits under the Social Security Act, the state must proceed cautiously in considering possible changes to income retention policy. DPA has identified several key findings:

1. Current eligibility rules concerning income retention may discourage persons receiving AABD medical benefits while residing in long term care from working even though employed persons may retain a portion of their earnings in addition to the $30 PNA.

2. Federal disability policy may also discourage persons receiving AABD medical as a result of having a disability from working.

3. Creating a more liberal income retention policy would facilitate the state's current efforts to comply with the *Olmstead* decision but is not the only mechanism to achieve this goal and in and of itself is unlikely to be sufficient to promote reintegration.

4. IDAs as currently prescribed by federal law, do not present a viable option to assist in reintegration. Other options under federal Medicaid law are limited or would have to be applied so broadly as to be too costly.

5. Allowing residents to retain either earned or unearned income is not in and of itself sufficient to assure reintegration to a community setting. The best outcomes would be expected where supportive services are available as well.

6. Advocates and persons with disabilities are divided regarding what criteria the state could reasonably apply when deciding who might accumulate income to support reintegration.

7. Because any increase in retained income must be offset by an increase in DPA's cost for a person's institutional care, changing the rules would initially cause state costs to increase. DPA's costs alone would be $1.5 million if just 500 individuals reintegrated from nursing facilities to their communities.

With these findings in mind, DPA will continue to work with DHS and DoA to determine whether income retention policy may be changed in a targeted and financially responsible way in conjunction with their ongoing reintegration projects.

This report will also be shared with the Older Adult Services Advisory Committee created by Public Act 93-1031 (SB2880) to promote transformation of Illinois' long term care system.

Appendices

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HOUSE RESOLUTION

WHEREAS, The United States Supreme Court decision in Olmstead ex rel. Zimring v. L.C., 119 S.Ct. 2176 (1999), held that persons with disabilities have a right to receive State-funded services and programs in the most integrated setting appropriate to meet their needs and to participate in community life to the fullest extent possible; and

WHEREAS, Many persons with disabilities now residing in nursing facilities in Illinois are able, available, and willing to engage in competitive employment or could be able and available to engage in employment if provided with appropriate supports; and

WHEREAS, Many persons with disabilities now residing in nursing facilities in Illinois are able and willing to live in more integrated residential settings; and

WHEREAS, Current Illinois Department of Public Aid rules limiting income retention by persons with disabilities residing in nursing facilities serve as a disincentive for persons with disabilities to seek or maintain employment; and

WHEREAS, Current Illinois Department of Public Aid rules limiting income retention by persons with disabilities residing in nursing facilities hamper the ability of such persons to transition to more integrated residential settings because they are unable to accumulate enough savings to consider other housing options; and

WHEREAS, Individual Development Accounts have proven to be successful in assisting low-income persons in meeting important financial, educational, and housing goals; and

WHEREAS, Allowing persons with disabilities now residing

in nursing facilities in Illinois who are employed or who will become employed to deposit a significant portion of their earned income into Individual Development Accounts for the purpose of saving for the transition to more integrated residential settings could result in greater economic independence for such persons; therefore, be it

RESOLVED, BY THE HOUSE OF REPRESENTATIVES OF THE NINETY-THIRD GENERAL ASSEMBLY OF THE STATE OF ILLINOIS, that the Department of Public Aid is directed to do the following:

(1) Conduct a thorough review and analysis of the current income retention rules for persons with disabilities who are residing in nursing facilities in Illinois in regard to the impact of the rules (a) on the implementation of the Olmstead decision in general and (b) on whether the rules create a disincentive to engage in gainful employment for persons who are able, available, and willing to seek employment with or without supports.

(2) Include in the review and analysis of current income retention rules recommendations on the feasibility of allowing persons with disabilities who reside in nursing facilities in Illinois and who are able and willing to move to more integrated residential settings to keep a larger portion of their income and deposit that income into Individual Development Accounts to allow for the accumulation of assets in order to transition into more integrated residential settings.

(3) Consult with the Department of Human Services, appropriate advisory councils and committees, persons with disabilities and their family members, advocates for

persons with disabilities, and other interested parties in conducting the review and analysis and developing recommendations.

(4) File a written report, including findings and recommendations, consistent with this Resolution, with the House of Representatives on or before December 31, 2004;

and be it further

RESOLVED, That the Department of Human Services shall cooperate in executing the requirements of this Resolution; and be it further

RESOLVED, That a copy of this Resolution be sent to the Director of Public Aid and to the Secretary of Human Services.

Illinois Department of Public Aid

201 South Grand Avenue East
Springfield, Illinois 62763-0002

Rod R. Blagojevich, Governor
Barry S. Maram, Director

Telephone: (217) 782-1200
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Meeting Notice
December 14, 2004
9:30 a.m. to 11:30 a.m.

Subject: House Resolution 851

House Resolution 851 resolved that the Illinois Department of Public Aid shall submit a report to the Illinois House of Representatives by December 31, 2004 regarding the effect of income retention rules on the ability of persons with disabilities to transition out of institutional care. Such rules govern the amount of income individuals receiving Public Aid medical benefits while residing in nursing facilities are permitted to retain rather than applying the income to the cost of their care.

A copy of HR 851 is available at:

http://www.legis.state.il.us/legislation/fulltext.asp?DocName=09300HR0851lv&SessionID=3&GA=93&DocTypeID=HR&DocNum=0851&print=true

Persons with disabilities, their family members, advocates for persons with disabilities and other interested parties are invited to attend to provide comments and ask questions about the report.

Date: **December 14, 2004**
Time: **9:30 a.m. to 11:30 a.m.**
Location: **Videoconference**

3rd Floor Videoconference Room
Prescott Bloom Building
201 South Grand Avenue East
Springfield, IL

DPA 7th Floor Videoconference Room
401 South Clinton Street
Chicago, IL

Questions or additional information prior to the meeting may be directed to Jacquetta Ellinger, Deputy Administrator, Division of Medical Programs, 312-793-1984.

Persons requiring special accommodations should call Carolyn Eddleton at 312-793-1984 or e-mail her at carolyn_eddleton@idpa.state.il.us at least 24 hours prior to the meeting.